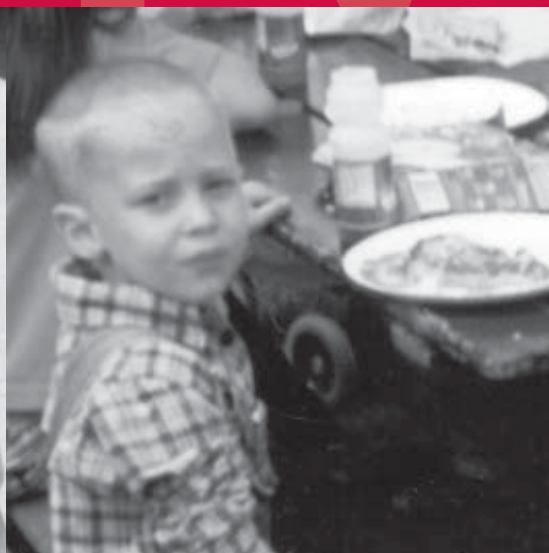


SESS

STARTING EARLY STARTING SMART



***The Starting Early Starting Smart
Family Strengths Institute:***
A Journal of the Convening

ABOUT STARTING EARLY STARTING SMART

Starting Early Starting Smart (SESS) is a knowledge development initiative designed to:

- Create and test a new model for providing integrated behavioral health services (mental health and substance abuse prevention and treatment) for young children (birth to 7 years) and their families; and to
- Inform practitioners and policymakers of successful interventions and promising practices from the multi-year study, which lay a critical foundation for the positive growth and development of very young children.

The SESS approach informs policymaking for:

- Service system redesign
- Strengthening the home environment
- Using culture as a resource in planning services with families
- Service access and utilization strategies
- Targeting benefits for children
- Working with families from a strengths-based perspective

In October 1997, with initial funding of \$30 million, the Substance Abuse and Mental Health Services Administration (SAMHSA) and Casey Family Programs embarked on a precedent-setting public/private collaboration. Twelve culturally diverse grantee organizations were selected. Each provides integrated behavioral health services in community-based early childhood settings—such as Child Care, Head Start and Primary Care Clinics—where young families customarily receive services for children. Critical to this project is the required collaboration among funders, grantees, consumers, and local site service providers. Implicit in the design of this project is sustainability planning for secured longevity of the programs.

The Study Design

The 12 grantees, working collaboratively, designed a study whereby integrated behavioral health services are delivered in typical early childhood settings. Each site has an intervention and comparison group, and each site delivers similar targeted, culturally-relevant, interventions for young children and their families. A collaboratively determined set of outcomes has been established to evaluate project effectiveness:

- Access to and use of services
- Social, emotional, and cognitive outcomes for children
- Caregiver-child interaction outcomes
- Family functioning

The goal of the SESS research is to provide rigorous scientific evidence concerning whether children and families participating in SESS programs achieve better access to needed services and better social, emotional, cognitive, and behavioral health outcomes than do the children and families not receiving these services. SESS programs may also generate information about opportunities, practices, and barriers to sought-after outcomes. This information is critical to achieving effective public policies.

SESS Extended

It was clear from the early days of SESS that whatever effects were uncovered, longitudinal extension of the study would be valuable. In 2001, SAMHSA and Casey Family Programs embarked upon an extension phase, which will increase understanding of the impact of early intervention as young children enter preschool and school years, when babies or toddlers are asked to meet escalating emotional and cognitive demands. This longitudinal extension can validate early methods and findings and assess their durability. It is anticipated that this work will include additional data points of a refined instrument set and intervention package with the addition of study questions related to cost and value, and other special studies. Additional future plans include applying and validating early SESS lessons learned, key concepts, components, and principles to new settings that serve families with young children.

Summation

In sum, SESS reflects the growing acknowledgement that it is important to target positive interventions to very young children. The infant and preschool years lay a critical foundation for later growth and development. Second, successful interventions for very young children must meet the multiple behavioral health, physical health, and educational needs of families. Third, integrated behavioral health services must be made more accessible to families with multiple needs, which are difficult to meet in a fragmented service system.

Early

The Starting Early Starting Smart
Family Strengths Institute:

A Journal of the Convening

Smart

Winter 2001

This paper was supported by Grants 5 UIH SP07974-8047 from the U.S. Department of Health and Human Services (DHHS), the Substance Abuse and Mental Health Services Administration (SAMHSA) and its three centers—the Center for Mental Health Services (CMHS), the Center for Substance Abuse Prevention (CSAP), and the Center for Substance Abuse Treatment (CSAT)—and Casey Family Programs. This report would not have been possible without the contributions of staff from DHHS, the SAMHSA Office on Early Childhood, Casey Family Programs, the *Starting Early Starting Smart* (SESS) principal investigators, project directors and researchers, and the parent representatives, who helped design and supervise the data collection. The content of this publication does not necessarily reflect the views or policies of DHHS or Casey Family Programs, nor does the mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government. Responsibility for the content of this report, however, rests solely with the named authors.

The families, grantees, and funders would like to acknowledge the significant work done by LaDonna Bonner. As the Family Representative to the SESS Steering Committee, Ms Bonner participated in the design, implementation, and evaluation of the SESS project from its inception. Her commitment to the families in SESS and her innovative role in the project required personal time and energy. We are forever grateful for her immense contribution.

Suggested citation:

Casey Family Programs and the U.S. Department of Health and Human Services (2001). *The Starting Early Starting Smart Family Strengths Institute: A journal of the convening*. Washington, DC: Casey Family Programs and the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

In order to plan the future wisely,
It is necessary that we
Understand and appreciate the past.

—Jo Coudert

Are we ready to take the first step toward change? If so, we need to stop, look, and listen to what families are saying. According to author Og Mandino, sometimes the best approach to perfecting a task is to “slow down and stop constructively.” In order to address the needs of families, let’s stop and construct new ways to move forward. When we take that first step, let the family lead the way.

Whenever there is a product and a consumer, satisfaction can only be guaranteed when marketing research is done; and so it is with the mental health consumer. How could the needs of a woman formerly addicted to drugs, raising and loving a child for the first time, be met unless she has had an opportunity to express her needs. In fact, the most well-read, educated scientist could only clinically anticipate her needs. In theory, she could resolve her problems; but only she could articulate her plight accurately. Only she, and others in similar situations, could relay the severity of issues that may be overlooked by a professional. Because it is possible for a professional to be fluent in the language of his or her profession and not understand that although a particular service is provided, issues as basic as childcare and transportation may inhibit access. One need only to attend a conference constructed and cofacilitated by families to grasp the urgency of incorporating families into the process.

*Listen to what I have to say;
Hear me with your heart
See my strengths regardless of my
Shortcomings,
Look at me through windows stained with
Compassion.
Respect my ideas, my experiences, my spirit,
And elevate your willingness to the height of
My mind.*

—Monica Baker

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FOREWORD

The design and convening of the Family Strengths Institute comes directly out of the family culture. This culture supports communication styles that are verbal and visual, evoking feeling and visual imagery; communication that is often rendered anecdotally and absent “alphabet” soup and clinical jargon. We suggest that this is just as valid a style of writing as a clinical one. Moreover, it is an appropriate style for communicating with and capturing the ideas and cultural mores of families.

Therefore the following document was prepared in a communication style that reflects “family” culture and demonstrates the validity and effectiveness of such a style in presenting work done by families.



BACKGROUND ON THE STARTING EARLY STARTING SMART FAMILY STRENGTHS INSTITUTE

The *Starting Early Starting Smart (SESS)* program is a research-based collaborative effort between the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Casey Family Programs, which studies integrated behavioral health services to children and families who have been impacted by environment, problems of substance abuse, and mental disorders. Operational in 12 sites in as many States, the *SESS* program provides these services in early childhood settings that are familiar to children and families, identifying the best practices for improving the developmental outcomes of young children from birth to 7 years of age.

The Federation of Families for Children's Mental Health was contracted by the Casey Family Programs and SAMHSA to conduct a Family Strengths Institute. The purpose of the institute was to learn from *SESS* families how to keep families at the center of care while empowering them in a meaningful participatory way in program implementation. In addition, the institute provided technical assistance to participants in developing advocacy skills to ensure optimal behavioral health for young children and families.

The purpose of this journal is to document the family involvement process in the convening of the Family Strengths Institute. The journal also describes the actual convening. The format of the journal includes guide points for involving families within the descriptive context to highlight points that are useful in transferring this experience to programs and services for families.

I. THE PLANNING PROCESS

The planning process for the institute had two basic components—development and design.



DEVELOPMENT

The first step was building a family team that would be responsible for the planning process. Federation staff decided to use a model that had proven successful in supporting and engaging family members in planning processes. This model included family members as mentors who had already gone through this type of planning process before and family members from the *SESS* sites who had never engaged in such an activity working together, assisted by Federation staff, a logistical planner, and a writer. This mix allowed the “newer” *SESS* family members to jumpstart their confidence in a very supportive environment that provided a comfortable and productive learning and sharing experience. Federation of Families Project Manager, Mary Telesford, identified four family member mentors, their selections based upon diversity, geographical location, language differences, gender, and past family leadership experiences. Short descriptions of the family member mentors can be found in Appendix A.

GUIDE POINT

It is important to build in the expertise of family member mentors when engaging family members who haven’t had the experience of participating in planning processes.

Using a contact list provided by the Casey Family Programs and the Federal partner, Federation staff enlisted the help of each site to identify a family member who could be a part of the planning team. After contacting the sites, seven family members were identified to work as part of the team. It was hoped that one family member from each of the 12 sites would be able to participate, however, for various reasons (from not being able to find a family member who could participate to not having enough time to identify one or due to overall program dysfunction with regard to family involvement) not all the sites were represented. Brief descriptions of these family members are in Appendix B. The family member mentors and the *SESS* family members formed the core of what became the Family Advisory Council for *SESS*.

The Family Advisory Council was convened for the first time in July 2000 for a 1½-day meeting. The meeting was facilitated by Federation staff and consultants. The family members' preparation and support before the meeting was primarily given by a consultant who had tremendous empathy for the parents. This consultant was a family member who had experienced the same sort of anxiety when she too became part of trainings and planning processes similar to the ones in which the *SESS* families were about to engage. This consultant paid special attention to meeting the specific childcare, transportation, food, and travel arrangements necessary for each family member. Provisions were made for family members to receive childcare, transportation, and food monies before they left home and a stipend was paid when they arrived at the meeting as a token of appreciation for their time.

There were family members who had never flown in an airplane before and/or were reluctant to leave their children with babysitters, which heightened their anxiety about participating in the meeting. In instances of this type the family member consultant was invaluable, because she took as much time as was necessary to support and nurture the family members.

The meeting began with dinner where family members were given the opportunity to meet and greet each other and Federation staff, as well as the Casey Family Programs staff members and SAMSHA staff members. The following day began the work of designing the Family Strengths Institute.

DESIGN

The day began with a leisurely continental breakfast. After breakfast there was meditation to set the tone for the work of the day. The initial introductions of all the members took approximately 2 hours. While this may seem an inordinate waste of time to some, it is critical to breaking the ice and providing a safe and confidential environment where family members could feel safe to discuss their personal issues. It was also important that the family member mentors began this process so that the *SESS* family members could benefit by their modeling.

After introductions the council was given its charge, to design a Family Strengths Institute. This institute was to serve as the beginning of family involvement in the *SESS* project, a valued but seriously underdeveloped component since program implementation began 3 years prior to the institute.

GUIDE POINTS

Family members need to receive childcare, transportation, and food monies before they leave home. In addition, stipends should be offered as a token of appreciation for their time.

A family member should be assigned the task of preparing and engaging other family members to participate in the planning process.

Family members need to meet, greet, and relax in an informal setting before the actual meeting begins.

Take as much time as needed to allow family members to tell their stories in an unrushed way during introductions.

The council engaged in brainstorming the question:

What do you think family members at your site would need in order to be more involved?

The responses:

- Childcare stipends.
- Transportation.
- Facility with a good atmosphere where they can feel free to come in.
- People they are talking to should have come from a similar situation—other parents who have been there.
- Outreach to parents (they don't know where to go to find the parents): go sit on the stoop, go to nail shops, laundromats, check-cashing places, etc.
- Outreach to fathers: get one father and he'll get the other fathers.
- Support of young parents (fathers and mothers) who are in recovery and trying to finish school.
- Teach young parents life skills: how to be independent.
- Lifestyle changes, e.g., having a baby as a rite of passage, change requires knowledge, and resources for options and lifestyles.
- Food.
- Aftercare—follow-up—continual support.
- Transitioning our kids into adulthood.
- Constant training for parents—different topics.
- Information and training—ongoing—in a place they know in their neighborhood.
- Families should select training and trainers offered in their neighborhood.
- Help me help my little boy go into manhood.
- Supports for the family.
- Ask families what they need and what workshops they would like to put on.
- Make services, trainings, etc., available at appropriate times for families.
- Family resource centers in the schools are only open during school hours.
- Acknowledge class issues, e.g., value of middle-class homemaker role vs. single parent trying to stay home and raise children—esteemed vs. marginalized and shamed.

GUIDE POINT

Family members respond well to brainstorming sessions. It is the responsibility of the facilitator, however, to synthesize the information in order to present it back to the family members in a way to continue with the planning process.

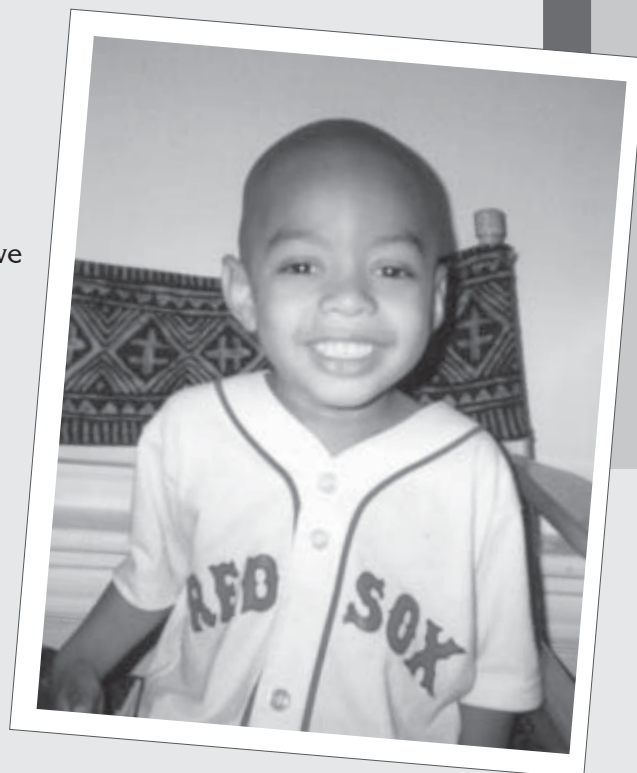
- My children look a different race than I am—people assume they are not my children—words like “half-breed” are used.
- Parents judged, stigmatized, and humiliated because of classicism and racism.

The second question brainstormed was:

What are the needs of family member representatives working in the SESS programs?

The responses:

- Listen to and use our ideas within the structure of the initiative they create. (What happened to recommendations we made 3 years ago?)
- It helps us to have our parent representative location be at the program site and to have transportation to offer other parents.
- Confidentiality—we are denied access to information about families that we are asked to help.
- Create a process that creates confidentiality within parent-to-parent support structure.
- How to promote ourselves as parent representatives (need training and peer mentoring).
- Information delivered to parent representatives in the community clearly and in their language, user-friendly language for parent reps.
- Create training tools, packages for parent reps to use.
- Help to create literature that is family-friendly.
- Professional tools/necessary resources to produce materials needed to do trainings, outreach, support, newsletters.
- Treat people the way we want to be treated, talk to them the way we want to be talked to. As parent reps, we must first be right with ourselves, know our limitations and know where we can expand. Respect community culture and the family culture, caution family reps to not create another bureaucracy.
- Parent reps need to be respected as professionals with expertise—families have their own expertise—not to have a family rep just because Casey said so.
- Parent reps need a building so that they do not come in as a social worker. Need a relaxed atmosphere—not in



GUIDE POINTS

Family members need scheduled breaks every 1½ hours to keep them engaged for the entire day's planning process.

Family members need to receive from the institute some information that will help them with their own specific families and children.

Family members felt that cultural competence with regard to race, ethnicity, and the family needed to be stressed to give all institute participants, especially professionals, a better understanding of how to value, support, and engage families in all aspects of the *SESS* program.

the mainstream system of care's therapeutic environment—staffed and operated by parents; parent-run and parent-driven.

- Parent reps need autonomy and authority to make decisions. When we work with families and get their hopes up about a training, etc., and then have it shot down by administration, we lose that connection and trust with that family.
- Local family organizations—501(c)(3)—strong infrastructure.
- Parent reps need to look at the whole family, not just the identified child.
- Parent reps need information about programs and other resources that are available—information about other disabilities and challenges—resource directory and referral system.
- If volunteerism is a value of that team, then everyone should be volunteering.
- Confidentiality clauses are applicable to “employees” only.
- Family reps need a network where they can reach each other.

The third brainstorming session addressed the question:

What are your roles now with SESS?

The responses:

- Represent parent teams in *SESS* getting into Healthy Start—volunteer not paid position. Work with paid staff person that I take into the community as the bullet-proof vest for the paid staff person. Sit on advisory panel for project. Babysit for families coming to classes.
- Employed by Boston Medical Center in a totally different capacity. Volunteer on the board of the *SESS* project where my children receive services.
- Participate on a steering committee as *SESS* parent rep to bring to professionals the parent's perspective—volunteer role. Have never been reimbursed for lost wages from job.
- As a volunteer, formed a parent group for parents with addictions.

After brainstorming and a much-needed break, the family members discussed how this information could help shape the agenda for the institute.

In terms of content it was important to the council that family members receive information that would help them understand how drug addiction and lifestyle had impacted the physical and emotional

development of their children. They felt that this type of information would assist family members in understanding some of their children's behaviors that may need professional help and support.

Secondly, there was a prime interest in addressing the value issue with regards to family members. In this regard, family members felt that professionals viewed them as projects and not people, and that their actual impact on the *SESS* program had been minimal because family members were not valued participants. They constantly spoke of their volunteer status with respect to the project and that others, particularly professionals, were paid and never expected to be volunteers. In addition, the council felt that cultural competence should be addressed. The council was clear that they felt the need to be understood within the context of their own racial, ethnic, and "family" culture.

The family members also were clear that they wanted to make presentations at the institute. It was decided that a presentation format using a family response panel would be an appropriate vehicle for expressing the family voices.

The next steps were self-selection into one of the following two committees: Family Continuum Committee and Value of Family Involvement Committee. A conference call schedule was set up and the committees agreed to help identify speakers and response panelists and to help shape the overall agenda.

During four subsequent conference calls, facilitated by Federation staff, the agenda was designed. There was particular interest in identifying speakers and presenters who would present in a way that was informative and interesting to families and who would ethnically and culturally represent the members of the advisory council. The Family Response Panels were comprised of council members who self-selected their panel participation based upon interests and life experiences.

GUIDE POINTS

Family members need to be a part of the presentations during the institute. The opportunity to speak and not just be spoken to is very empowering to the family members presenting and affords good modeling of family members' abilities for all institute participants.

The committee structure for planning the institute gives family members an opportunity for continued participation without overburdening them with too many tasks.

A facilitated process that is staffed and scheduled by a contractor (in this instance the Federation of Families) is needed to support the ongoing planning process that requires conference calls, mailings, and e-mails.

II. THE CONVENING

Starting Early Starting Smart
Family Strengths Institute

DAY 1— OCTOBER 19, 2000

Registration was held between 3 and 6 p.m. This allowed time for arrival and settling into rooms before dinner.

Registration was handled with as much care and sensitivity as every other aspect of the institute. In order to give family panel members the confidence that their presence was of the utmost importance, each one was greeted and made to feel welcome and comfortable. Family members were given the same packet of information as professionals. Each was given a nametag but no distinctions were made between professionals and family members. This allowed for freedom to meet others without prejudging them.

Because of the smooth flow of registration the tone was set for the first night of greeting and meeting. The professional, yet supportive, way in which registration was handled was due in part to B-C Family Productions. B-C's principle owner, Scott Bryant-Comstock, and staff can be credited for the handling of details from travel arrangements to special dietetic needs at meals. Due to the fact that many family representatives had never traveled without their children, or had never traveled by air, the kindness administered by Mr. Comstock and his staff was very important.

Dinner was served between 6 and 8 p.m. in a formally arranged dining room with large round tables and no designated seating assignments. The dinner was only for family members in order to encourage free-flowing conversation and uninhibited interaction. Families were able to eat and pass around pictures of their children and bond. The need for comfort and the freedom to be oneself was extremely important to setting the tone for the whole conference.

Some complaints were made by professionals for not being able to participate in the family dinner. Accommodations were made by B-C Family Productions for them to eat in a restaurant in the hotel. After discussion with Federation of Families staff, it was understood and respected that a "families only" dinner was necessary. However,



GUIDE POINTS

A comfort level needs to be established at the onset, during the registration process, so that family members and professionals understand that both are necessary for a positive outcome from the institute.

It is important for family members, especially for those new to these types of meetings, to relax with other family members and to gain additional encouragement and information from meeting facilitators before the actual convening.

because the agenda and the hotel marquee indicated only a “dinner,” some professionals felt misled and misinformed. With the exception of the complaints regarding the exclusivity of dinner, all else went well.

Barbara Huff, executive director of the Federation of Families for Children’s Mental Health, gave a fitting welcome and introduced the *SESS* Advisory Council, Federal partners, and Federation staff. She thanked the participants, stakeholders, and Mary Telesford. She emphasized that family experiences, good and bad, “should drive this system,” and until such time, there will be services that don’t meet needs. “This,” she said, “is the reason for the institute.”

Mary Telesford commented, “Researchers forget completeness. They approach projects not people.” She said that we must move away from the deficit model approach and realize that what makes families resilient in spite of challenges is strong history and tradition. “Families lead the way!” Before dinner ended Mr. Comstock handed out prepaid telephone cards so that family members could call home.

Substance abuse support meetings were provided by a trained substance abuse counselor every night following dinner. These meetings were held in a suite away from the traffic of other institute participants and hotel employees and lasted 2½ hours each night. The meetings were open to everyone, but to maintain the integrity of participants, meetings were open only to those needing this service.

After 8:30 p.m., nothing was scheduled on the agenda.

DAY 2—OCTOBER 20, 2000

Registration continued for those participants who had not arrived on Day 1. A continental breakfast was available at 8 a.m. A beautifully arranged assortment of fresh fruits, juices, breads, and pastries was available. The spread, which accommodated a variety of tastes, could have easily symbolized the diverse experiences that were about to be shared this day.

The morning began with Shannon Crossbear, a native of Fort William First Nation of the Lake Superior Ojibwa, offering a prayer reflecting her American Indian culture.

Manaja Hill, a parent mentor with the Family Advisory Council began the morning presentation by describing the “circle of life,” a conceptual framework that orders the life experience from a Native American perspective. Within the circle of life, the four directions not only are navigational tools but are representative of the different races of man: north is black, east is red, south is white, and west is yellow. To lead the most fulfilled life, the four values, which guide living, are generosity, sharing wisdom, bravery, and humility. And ultimately it is understood that man/woman lives through seven

GUIDE POINTS

Professionals need to understand that their presence at the initial family activity would inhibit the empowering and networking processes that are critical to preparing family members for institute participation.

Family members many times do not have credit cards, so access to hotel phone service and even check-in is difficult. Therefore, prepaid telephone cards and setting up master billing for hotel check-in avoid inconvenience and embarrassment.

The support of substance abuse meetings during the institute helps family members continue their regimens of sobriety.

GUIDE POINTS

Beginning the day with a demonstration of spirituality prepares institute participants emotionally and mentally for the activities of the day. This also affords an opportunity to demonstrate cultural competence, for this activity can be expressed through various cultural frameworks.

Given the opportunity to present on issues and topics other than their personal stories helps to break down the stereotype of family members as “just consumers.” (Please go to the Appendices for brief descriptions of other family member presenters.)

Presenters should use a strength-based approach regardless of topic.

stages of life, from birth to death, setting the stage for the next generation to experience the circle of life.

Mary Telesford gave a presentation on the resiliency of families. Ms. Telesford stressed the need to view families from a strength-based approach. She spoke of the qualities that sustain many families, such as spirituality, quest for a good and higher education for their children, community involvement, strong support system, and sobriety, in spite of the challenges of poverty, drug addiction, and under/unemployment. Further, she stated that these qualities, which lead to resilient behaviors, need to be introduced to support families that are not coping well with the aforementioned challenges. This strength-based approach, unlike the deficit model approach, ultimately leads to better outcomes for children and their families.

The rest of the morning was spent absorbing a plethora of stories from family panel members. A common thread linked their experiences: the revelation that the systems that were in place to help them overcome their different barriers could not accommodate diversity, ethnicity, spirituality, or even begin to address their specific needs. From Shannon Crossbear’s American Indian experience with the mental health system to Angelica Andino’s (chairperson, board of directors, Abriendo Puertas, Miami, FL) admission that Latino families do not share their hardships with other family members, much less go outside of their households to ask for help, it was evident that if any change was going to occur it must begin with them. The stories of struggle varied but family members could relate to each other’s perseverance. Their stories stimulated applause, and at one point a standing ovation. Many found it hard to hold back tears when stories shared included children separated from their families or a mother expressing feelings of shame or guilt. The stories of struggle caused the listener to walk a mile in the shoes of the panel member telling the story as opposed to evoking feelings of pity. It is important to families that they hear and share their experiences. They wanted to pave the way to an accessible road. They all agreed that each stone laid along this path must be placed by the family. And for those who seek to administer assistance, they must be led by the hand of the family.

Families know that to effectively be the center of the formula for success, they must embrace education. And they listened intensely as Dr. Gloria Johnson Powell, director of race, ethnicity and medicine, and associate dean of faculty development at the University of Wisconsin, educated them, bringing to life the adverse effects of different drugs used by pregnant women on the newborn child. She simplified these agents and effects, which could have been complicated and very clinical, into terms, illustrations, handouts, and overheads that were understood by everyone. This portion of the

conference was very informative, particularly to parents who were able to link some of their children's behaviors to their own drug use and abuse. This also helped family members identify behaviors in their children that could require clinical assessment and/or intervention.

Following Dr. Powell, more family panel members shared their stories of what led them to advocate for the needs of their children. Some spoke of generational malfunctioning while others told of the innate desire to rescue another family member from the grip of addiction. Again, the underlying note was discovering ways to overcome adversity.

The stories left everyone in resolution mode. Professionals as well as family members were eager to come together and identify strategies that would bridge the gap between them. Some professionals said that they felt revitalized and renewed in their professions. Others said they had never experienced a conference that captured their undivided attention. One gentleman said that he was impressed with the cover of the conference notebook because it featured a picture of a father holding his daughter. And as a male professional, listening to a predominately female panel, it was inspiring to see that the male represented in the family wasn't invisible. In order to maintain the level of enthusiasm and capture the ideas evoked from the presentations, two groups were formed. Dismissed to separate conference rooms, the professionals were commissioned to develop engagement and outreach strategies and the family members to develop a plan of advocacy.

The Family Member Group

This group was facilitated by the family member mentors of the *SESS* Family Advisory Council. One professional who had identified with the family member group because she has a son with special needs, was kindly asked to leave and participate in the professional group. In an effort to protect the family member group and not have any professional's influence, they felt it best for her to participate in the capacity in which she registered for the conference.

The question:

What do parents want from the SESS program to help their families?

The responses:

- A group to mentor parents; to make sure parents know how to get needs met through program entitlements.
- Vocational training to find better jobs.
- Transportation.

GUIDE POINTS

The response panel format allows family members a good vehicle for telling their stories and experiences within a topical framework.

Presenters should make every effort to convey information in language, with visual aids, that everyone can understand.

“Family members” are those persons who were selected, based on their experiences and involvement with the *SESS* program, to represent the family voice(s) for a site team.

- An emergency fund.
- Counseling with a spiritual rather than psychological approach.
- Childcare for working parents.
- Fight against discrimination of resources for undocumented immigrants.
- Have parents evaluate intake process and make suggestions.
- Look closer at parent involvement in future research projects.
- More father-friendly programs.
- Information clearinghouse; professionals providing information via newsletter, monthly meetings, group-thinks.
- Overcoming language barriers.
- Flexibility of professionals, office hours, program locations to better serve families; involve other *SESS* partners to change their old ways of delivering services to families; create a family system of care.
- Educational information regarding children's mental health books.
- To deal with programs that don't support families, i.e., HUD policies that discourage parents formerly involved in criminal justice from living together.
- Professional support for families and empowering them to act on their own.
- Legal clinics.
- Push to educate, train, and hire family member caseworkers, e.g., train welfare-to-work project.

GUIDE POINT

Family member mentors from the Advisory Council can serve as facilitators in smaller break-out sessions with the parents and/or professionals.

The Professional Group

Professionals seated themselves with other members from their site. This session was facilitated by Mary Telesford, Federation of Families, and Velva Spriggs, Office of Early Childhood, Substance Abuse and Mental Health Services Administration. Notes were taken on large white paper and taped to the walls as they were filled with "barriers and challenges in family involvement." The final draft looked like this:

Barriers/Challenges in Family Involvement:

- Stigma of mental health: cross-culturally.
- Accessibility; flexible work schedule; motivating workers to work outside 9-5.
- Mistrust of agency; mistrust of consumer by agency.
- Transportation.
- Language.
- Knowledge of resources.

- Not enough hope.
- Unrealistic expectations; uninformed referrals.
- Telephone access.
- Long waiting lists.
- Other agencies not respectful of process; not in sync with *SESS*.
- Illegal status prevents access to needed service.
- Parent readiness to venture out.
- Social services view: “last chance parents”.
- Intra-agency/Interagency territorial battles.
- Models of mental health and substance abuse programs don’t meet needs/expectations of families; inflexibility of old recovery models.



Once the barriers and challenges were brainstormed, the group self-selected to address some strategies and remedies, in small group discussions. After these small group discussions, an open forum for feedback was provided. Many of the strategies included getting support, which is very much needed, from other professionals to work in a pro-family way. Many felt that even though they wanted to try to work differently in terms of families, they were hampered by the policies and guidelines of the bureaucracies and agencies for which they worked. They also shared that creativity and a little risk-taking were sometimes necessary to support families in the best way. Many showed great commitment to family involvement in the treatment and delivery of services. Others felt that cultural competency was an issue that needed to be better understood in order to serve families better.

DAY 3—OCTOBER 21, 2000

After breakfast Gail Daniels offered an Arabic prayer that set the spiritual tone for the day. Dr. James Mason, senior project consultant at the National Center on Cultural Competence, Georgetown University Child Development Center, then began a presentation on cultural competence.

Dr. Mason stressed the need to read about cultural competency and suggested that the audience get copies of *Towards a Culturally Competent System of Care, Volumes I and II*, offered by the National Technical Assistance Center for Children’s Mental Health at Georgetown University Child Development Center. (Velva Spriggs offered to make these publications available to all institute participants.) Dr. Mason’s presentation was delivered in a very humorous and entertaining way.

A lot of good information was given about how to incorporate cultural competence into one’s thinking on a personal level, as well as



at the system assessment and delivery levels. On a personal and practical level, Dr. Mason stressed that making assumptions about another person's culture can often lead to surprises, so when in doubt, just ask. With regard to systems, Dr. Mason stressed not only the need to listen to families but to understand that within the family culture there are several cultures that need to be understood in order to effectively assist families, and again, don't make any assumptions.

Dr. Mason, while cautioning against making assumptions, did provide specific things that one might review when trying to better understand another culture. These things included: type of food, religion, geographical location, race, ethnicity, gender preference, type of dress, social mores, language differences, patterns, and dialects. Again, while these things may be helpful they certainly are not definitive in understanding culture and making one culturally competent. Dr. Mason's parting words were, "When you think you may have achieved cultural competency look again, because there is always something else you can learn about a new culture that is soon to come your way."

The Family Response Panel highlighted how it was important to have professionals who work with their children and with them, understand who they were and what they have gone through and, just as importantly, how to assist families through their personal empowerment processes. The panelists also stressed the need for professionals to listen more to families when treating their children. Another panelist spoke of the need to have professionals that spoke their language, especially when it was not English.

The next session, the Role of Families in Research and Evaluation, was conducted by Elaine Slaton of the Federation of Families for Children's Mental Health; Shannon Crossbear, an Individuals with Disabilities Education Act trainer from Fort William First Nation of the Lake Superior Ojibwa; and Jacky McKinney, who works with a SAMHSA-funded study on women with co-occurring disorders and violence. Ms. Slaton, Ms. Crossbear, and Ms. McKinney stressed the need for family members to understand research tools and techniques so that they would not become "victims" in a research study. They addressed the right of the family members involved to be able to feel safe in the research experience and to receive some benefit from it. In terms of evaluation, family members have been invaluable in helping review and design evaluation tools that reflect findings useful to family members and professionals alike. The overall message of this presentation was that research is not totally objective, and in fact can be quite subjective if there is no input or feedback loop to the family members being researched.

Lunch was followed by site-specific planning sessions that joined the professionals from each site with their family members. This was an

GUIDE POINTS

Presenters who can present information in a creative and entertaining way should be sought to participate in the institute.

Families are supported and served best by professionals who work in a culturally competent way.

Subjectivity in research is lessened if there is input from and feedback to the persons being researched.

opportunity for the family members and the professionals to use the outcomes of the activities of their separate brainstorming groups to come together and design a plan of action that they would implement together when retuning home. These sessions were facilitated by family members from the Advisory Council and the Federation staff. After a break, each site reported back their action plans. (All site plans were collected, typed, and given to every participant the next morning.)

An awesome party ended the day's activities. A buffet of tasty morsels was spread across the front of the party room. The aroma of wing dings, mini pizzas, and an endless supply of other finger foods decorated the room. The DJ played a variety of music to suit the diverse crowd. And a child led them to the dance floor. As she danced around to each table encouraging everyone to join her, the spirit of the institute was captured. Everyone, professionals and family members alike, danced side-by-side with the pied piper child leading them in the electric slide.

DAY 4—OCTOBER 22, 2000

The morning of departure began with the same continental breakfast. Some complained that there had not been enough variety, or enough coffee. It may have been the anticipation of one more meeting before the flight home or the hustle and bustle of checking out. For professionals, who may be familiar with this routine, it may not have been stressful, but some family members looked a little tattered (maybe it was the party the night before). In any case everyone gathered for the last time to put a cap on the findings of the previous meeting. Cherie Craft offered a prayer to set the spiritual tone for the meeting one final time. Mary Telesford made closing remarks as everyone trickled out to go to their separate ways. The Family Strengths Institute served not only as a learning tool to discover the needs of families, but also presented the opportunity to put into practice those things that families say they need to become an integral part of the process.

Upon leaving, many family members commented that they felt heard and empowered for the first time since they were a part of the *SESS* program. Their spirits were captured in the following poem, by Monica Baker:

*Listen to what I have to say;
Hear me with your heart
See my strengths regardless of my
Shortcomings,
Look at me through windows stained with
Compassion.
Respect my ideas, my experiences, my spirit,
And elevate your willingness to the height of
My mind.*

GUIDE POINTS

Working together as a site team jumpstarts the process of demystifying professionals for family members and helps professionals see family members not just as consumers. In addition, having planned continued interaction on returning home helps to build the family member/professional relationship that ultimately affords better outcomes for the family members and their children.

Playing/socializing together helps to build relationships other than professional and consumer.

III. FAMILY STORIES

A PREFACE TO THE FAMILY STORIES

To a person who has never done drugs, it is a mystery and somewhat baffling to try to

understand what causes someone to do drugs.

For someone who has always had the privilege of being privileged, unemployment, poverty, and homelessness are remedied simply by “getting a job.” In a time when technology has allowed us to communicate via multiple forms of media it is difficult to imagine that the effects of alcohol, drug use, or unprotected sex are not understood by all; at least those residing in the United States. To one thinking rationally, it is amazing to think that someone armed with knowledge would engage in momentary lethal pleasure.

But it is the nature of people to think more of ourselves than we ought and less of ourselves when we should be exalted. It is also in our nature to take risks and attempt to beat the odds. Thus, we find ourselves, in spite of common knowledge, battling against enemies that we have released upon ourselves; looking down the barrel of a loaded gun and realizing our own finger is on the trigger.

From presidents to celebrities we have become a Nation engaged in self-destructive behavior. We are all on the giving or receiving end of study, analysis, treatment, or counsel, constantly trying to provide or receive service that is politically correct or user-friendly.

From presidents to celebrities we have become a Nation engaged in self-destructive behavior. We are all on the giving or receiving end of study, analysis, treatment, or counsel, constantly trying to provide or receive service that is politically correct or user-friendly.

With the spoils of our wars we attempt to rebuild lives. It is no wonder that in spite of legislated, legal, clinical, or scientific efforts, it is when people have moments of revelation for themselves that they are able to gather themselves, collect their tools of competency, and act in a manner that promotes life. Once we have personally experienced this revelation, when academia, common sense, science, and spirituality collide, then are we able to appreciate and learn from those who have suffered. For it is out of this experience that we can administer help to one another professionally and humanely.

The women in these stories represent the families of the SESS (Starting Early Starting Smart) projects. SESS is a program that is



committed to reaching families by using child- and family-centered approaches. The names have been changed but the stories are accurate. When told by the women, these stories are alive and escort the listener into a world as raw and dramatic as any movie. However, the glimpses into the lives of these women are their reality, not fiction. Understanding these stories is integral to understanding how to serve families in similar situations.

As you read these stories, look for the universal themes of our human experience—fear, tragedy, loss, shame, yearning, turning points, striving, restarts, disappointments, hope, faith, love, forgiveness, reconciliation, and dreams. Embrace our common humanity!

LINDA'S STORY

Linda is a parent representative on the *SESS* Steering Committee in her community. She is a 29-year-old mother of four children. Because of progress she has made rerouting her life from addiction to sobriety, she was selected to participate on the *SESS* Steering Committee. She strives to assist with family involvement. Because of her life experience, she is able to give realistic ideas of how families dealing with drug addiction and children's mental health issues can benefit from different programs and services. Her story gives hope to others.

Ultimately, she would like to see parents involved at every level of planning services. She feels that parents need to have a better understanding of the research process, otherwise they get lost in the jargon. Her opinion is valuable considering the path that has brought her to such a fervent commitment to help make change.

Linda's ability to form such rational opinions is nothing short of miraculous. In hindsight, she marvels at her own successes. But not even the benefit of 20/20 hindsight can help rationally explain why she ever started using drugs. When you delve into her past there is little indication that she would ever consider drugs an option. When she describes her childhood, it includes all the elements of a successful future. She is an identical twin and one of five children. Her mother, a college graduate, worked hard so that she could provide sufficiently for her children. Linda went to Catholic school, and she attended church regularly. She was an honor student, a peer leader, and she looked forward to going to college. She considered herself strong-willed and level-headed. However, she offers no rational explanation for the events that follow.

Although this is Linda's story, it is necessary to subdirect this story to her identical twin sister, Laura, who preceded her in addiction by 2 years. Married at 17, Laura and her husband got high daily. They

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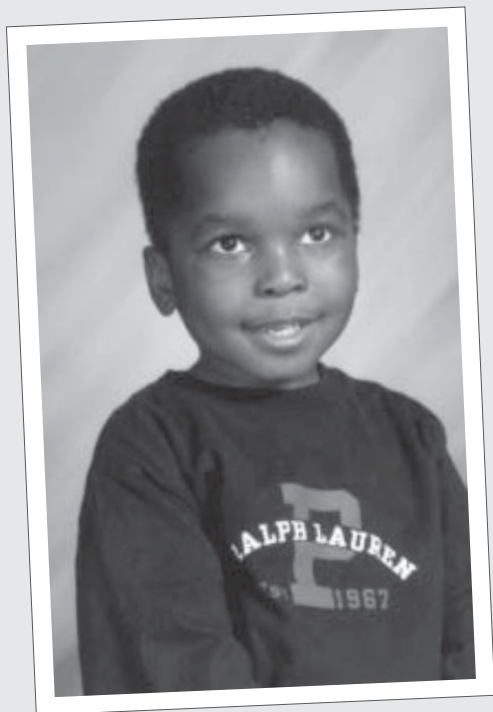
eventually lost custody of their child. It is important to note that Linda was hurt deeply by what her sister was going through. She watched Laura melt down to 98 pounds as crack cocaine took over her life.

After entering college in 1989, Linda became pregnant and involved with a drug dealer who was abusive. The evening prior to her delivery she had an argument with her boyfriend. In an effort to relieve her stress, she went to her sister's house and smoked crack for the first time. Linda has no rational explanation why she considered smoking crack cocaine during the ninth month of her pregnancy; only that she thought she was strong enough to bypass addiction and experience only stress relief. She gave no consideration to the fact that she could give birth, and potentially introduce drugs into the system of her unborn child.

Fortunately for the baby, Linda went into labor the next morning. Because she was high at the time of delivery, Child Protective Services was called in to investigate. They opened a case and monitored Linda and her baby girl for the next 3 months. She was able to trick her caseworker into believing that she had stopped using drugs for the required 3-month probation period, when in fact, she had never stopped. Linda found herself pregnant again within a few months. She still continued to use.

Although Linda's boyfriend was a drug dealer, he had enough sense to know that his children were not safe with a drug addict. He threatened to leave and finally did so. She was unable to pay her bills and she was facing eviction. She claims a moment of clarity when she tricked her boyfriend into taking the two children to her mother's house. She decided that it was wrong for them to suffer as a result of her drug addiction. She felt that they would be better off with her mother, than to be homeless with her.

Linda started dating someone else and got pregnant with her third child. It is at this point that she experienced a breakthrough. A moment of clarity for a drug addict is that one moment in a plethora of absurdities that makes complete sense. Linda considers that moment to be when she strapped those two children into her boyfriend's car and ran in the other direction. It truly came later at the sight of a friend's premature infant. The tiny baby, born 3 months early, suffering from fetal alcohol syndrome and clinging to life by an intravenous tube, saved her life. Linda, 6 months pregnant, realized the probability of her unborn child suffering from similar birth defects. Considering the fact that she had, for the duration of her pregnancy, consumed crack cocaine, she contemplated the complexities of caring for a child that was deformed or abnormal in some way. The sight of this less-than-one-pound shadow of a baby



quenched her insatiable desire for drugs. This marked the beginning of her road to recovery.

This story is 7 years behind Linda, and the experience now serves to help others. Linda is currently a junior, liberal arts major, at a university near her home. She is raising her ex-boyfriend's 12-year-old son, along with her own three children. Two of her children have mental and learning disabilities as a result of her drug abuse. However, she has been able to receive guidance and assistance from *SESS*. She has learned to help other families in crisis and has lent herself and her story in order to make changes in the lives of families.

Ten percent (20 million) of adult Americans are currently divorced. Twenty-eight percent (20 million) of all children under 18 years of age in the United States live with just one parent. What about the children?

rita's STORY

Rita's parents divorced when she was just 3 years old. She and her four sisters lived with her mother. By the time she was 11, her father had married a woman with a son the same age. Rita and an older sister moved in with their father. Since the two sisters were close in age to their stepbrother, Rita's father decided that it might be a good idea for them to live with him. She recalls not wanting to move in with her father because he was an alcoholic. Also, he was not having a good relationship with her stepmother.

Rita remembers drinking alcohol with her father as early as when she was 12 years old. Not long after she began to drink, she started smoking marijuana with her older sisters. Drinking and smoking led to amphetamines and finally crack cocaine.

At the height of her addiction, Rita was 21 and pregnant. Something about pregnancy and the thought of harming an unborn child caused her to rethink the severity of her drug addiction. In the midst of self-destructive behavior arose a maternal desire to save her child.

This saving grace for Rita occurred 3 years ago, during her fourth month of pregnancy. She realized that her lifestyle could potentially cause some complications for her unborn child. She admitted herself to a drug rehabilitation program at a local university hospital and to date has maintained sobriety. She enrolled in Los Niños, a service provided during rehab that monitored the development of her unborn baby.

In February 1998, Rita gave birth to a baby girl. The baby suffered from social anxiety, which made it very difficult for Rita to take the

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As a young child of 5, Barbara witnessed a chaotic and violent scene that involved her own father impulsively stabbing a man in front of her family home. . . . After her parents' divorce and her father's 6 years in prison, he passed on a life lesson to his 10 children, stating they should always remember, "if you have a moment to think (before you act), do it!" For several years of her life, Barbara did not always follow her father's advice, but rather followed his example.

baby away from home. A trip to the grocery store could prove to be a disaster. Rita carried a burden of guilt about her daughter's problems. She sought help from her caseworker, who referred her to participate in a local *SESS* program.

Rita participated in a number of services provided by the *SESS* project. Her daughter was seen regularly in the program's primary healthcare clinic for well-child visits. Based upon the results of developmental evaluations, Rita was referred to and received specialized early intervention services to ameliorate developmental delays. In addition to receiving case management and home visiting services, Rita attended parenting groups onsite and also accessed the free legal services the program offered.

Rita was an ideal participant. She assumed a leadership and advocacy role on the Family Solutions Committee. She credits the program for educating her and providing her with counseling services that benefit her daughter. Now, with self-esteem intact, she is important to her community; serving as a liaison between the community and *SESS*. She would like to be instrumental in establishing more contact with parents in similar situations.

Rita continues to move forward and is setting a positive example for others. She volunteers as the executive parent representative on the Family Answers Committee. This committee is a group of parents that meet monthly with casemanagers to address parent concerns. She also works for the city government's planning department. Her job has allowed her to network with local private business owners. As a result, she has spearheaded a fundraising project. All funds collected will help subsidize fees to attend future Family Strengths Institutes.

Rita has acquired the ability to speak in front of large groups. On January 22, 2001, she addressed the State legislature concerning legislation for prenatal nutrition classes. She not only prepared the speech, she also researched all existing legislation on the subject. She also made a presentation at a symposium in April 2001. She is amazed at how much respect she is receiving from her community. She never fathomed that the experiences in her life would result in such positive activity.

BARBARA'S STORY

(Barbara's story was authored by Barbara herself, with input from the project director of her SESS site.)

At the age of 44, Barbara can see that certain critical life events have been associated with both her initiation of drug use at age 13, and the maintenance of her now 4-year recovery from drug addiction. In

addition, evidence of Barbara's core strengths of adaptability, resourcefulness, sociability, and concern for others can be seen throughout the ups and downs of her life.

As a young child of 5, Barbara witnessed a chaotic and violent scene that involved her own father impulsively stabbing a man in front of her family home. Her cloudy memories of this event did not surface until her adult years, and she would later hear that her father incorrectly believed this man to be having an affair with her mother. After her parents' divorce and her father's 6 years in prison, he passed on a life lesson to his 10 children, stating they should always remember, "if you have a moment to think (before you act), do it!"

For several years of her life, Barbara did not always follow her father's advice, but rather followed his example. She began using alcohol and marijuana at the age of 13, and was addicted to crack cocaine by the age of 26. Her suppressed emotions found an outlet as she became more deeply involved in the drug culture through both using and selling illegal drugs. She describes her encounters with the men in her life as motivated primarily by her need for money to buy food and drugs. Barbara found that for 6 years she was able to maintain this life while also parenting her daughter Sharlene, born when Barbara was 27. However, this balance was disrupted when Barbara was convicted on felony charges of aggravated battery. She would eventually serve 5 years in prison while her mother assumed parental responsibilities for Sharlene.

Although Barbara found no help for her addiction while in the prison system, the experience would have a profound impact on her life. Upon release, faced with the loss of her civil rights and poor employment and housing prospects because of her felony conviction, Barbara returned to familiar lifestyle habits. For 3 years her mother maintained custody of Sharlene, which Barbara believed was best. During this time, a chance encounter with three children she met through a friend would begin Barbara on the path home for help. With no one willing or able to care for them, Barbara's heart pulled her to step in temporarily until their mother was released from jail. She describes the experience as reconnecting her to her own spiritual side and giving her a positive sense of purpose. It also made her realize the void she felt from not taking care of her own child, who was now 14. Additionally, Barbara's discovery that she was pregnant made her feel as if she'd been given a second chance. She returned home to her family and voluntarily entered a maternal addiction program for pregnant women.

Upon giving birth to a healthy baby girl, Cassandra, Barbara learned of the *SESS* initiative in her community. Motivated to be the best mother possible to both her girls, she enrolled and has been actively





involved with the program for the past 3 years. An exemplary participant, Barbara has taken full advantage of all the services available, including parenting groups, prevention topic presentations, individual counseling, and care coordination. She completed three 12-week parenting groups, including *Baby & Me*, and two rounds of *Strengthening Multi-Ethnic Families and Communities*, seeking additional support and information about parenting. Barbara reports a greater understanding of child development and behavior through these activities, which has enabled her to be a more patient parent when dealing with normal stresses of raising an adolescent and a toddler at the same time. As she says, “they keep me balanced.” Barbara explains that prior to her *SESS* enrollment, she had been accustomed to doing her “own footwork” to find resources and get what she needed. She says that when she was able to “drop the fear” of relying on outside help, she found she could go even further by combining her own resourcefulness with the support and suggestions offered by *SESS* staff. The relationships with *SESS* staff have helped Barbara to realize, “I can be a good example to my own kids and family, as well as to other parents” who may be in stressful situations.

Barbara’s strong desire to apply what she has learned to improve both her family life and the lives of others, through sharing peer support and resources, has been demonstrated in her commitment as the local *SESS* Parent Representative. She has done volunteer work assisting *SESS* parenting educators conduct classes, attended national parent involvement and empowerment meetings, and successfully recruited and organized a biweekly parent network group. Barbara’s “people skills” allow her the ability to connect with and speak for others with similar experiences, and her enthusiasm engages others to become involved in positive change in their lives and communities. Even in the face of life’s challenges that always eventually arise, Barbara maintains an optimistic outlook and a mission to improve the world around her.

CHARLOTTE’S STORY

Looking at the statistics regarding divorce, drug abuse, domestic violence, or child abuse, we are given a bird’s-eye view. But we must have microscopic vision and see faces, not cases. Charlotte has one of those faces that we ought to look at and learn from. In observing her life we learn that there is hope, even in those who seem the most hopeless. We can never underestimate the power that a tragedy has to change a life for the better.

Charlotte’s parents divorced when she was in the fifth grade. This was a tragic event for her and marks the beginning of many tragedies to follow. After the divorce Charlotte’s mother had to work longer hours to take care of her three children. Often the children were left



home alone. Charlotte's feelings of anger and loneliness became overwhelming. In the fifth grade she turned to marijuana as a form of entertainment. At a time in a little girl's life when she should play with dolls, Charlotte was smoking joints. Of course, this radically changed her behavior, and her mother became concerned. Charlotte rebelled against (what she considered) her mother's constant badgering. Like many preteens, she felt that her mother just didn't understand the complexities of her life. Charlotte believed that at 12 she was more than capable of taking care of herself, so she ran away from home. Unfortunately, this was not a childish scenario where the little girl takes her sleeping bag and a sack lunch out to the backyard for the night. Charlotte moved eight blocks away from home to a drug house. For a whole year she lived in the backyard of the drug house with other runaways. Her mother had no idea where she was and constantly checked the city morgue for young "Jane Does." After a year, Charlotte returned home and at 14 became pregnant with her first child. Having been exposed to drugs, sex, and violence, it was even more difficult for her to submit to her mother's authority. She continued using drugs and eventually moved in with her 19-year-old boyfriend.

By the time Charlotte was 20 she had three children, an 8-year drug addiction, a drug-addicted live-in boyfriend, and several drug convictions. Her eye-opening experience came through tragic loss. After losing her home she voluntarily placed her children in foster care and soon thereafter her boyfriend died of a drug overdose. This string of tragic events shocked Charlotte into a reality that allowed her to see herself as an addict and a neglectful mother. Charlotte checked into a drug rehab program. At a transitional living center, she took parenting classes that taught her how to relate to her children.

At this point Charlotte was determined to stay drug-free and be the parent she had not been. The change in her attitude was obvious, and a counselor noticed that she had the potential to help others by sharing her story. Her counselor referred her to a *SESS* project and she became a family representative.

With the help of the *SESS* project, Charlotte is now successfully taking care of her children and herself. She credits the program for providing her with the necessary counseling and resources that have enabled her to become organized. The program also provides anger management counseling for her oldest son. She considers the other program participants a "second family."

Charlotte has restored her relationship with her mother and is employed by her mother's home remodeling company. In addition to working full time she is committed to meeting weekly with eight other

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parents at the Casey Family Partners (CFP) site. She goes door-to-door in her community passing out fliers and spreading the word about all the good the program has to offer. She would like to see a partnership formed between CFP and the local Narcotics Anonymous.

Although her group is not large, Charlotte is hopeful about continued growth. She believes that people in her community are hesitant, because they don't trust that their plight will be understood. Charlotte is on a mission to let others know that she can relate and that there are organizations with services that can meet their needs. She hopes to continue sharing her story with other families and help the Casey Family Partners change lives, one family at a time.

Two children running down a hill take a fall. Both scrape their knees and must bandage their wounds. Upon removing the bandages one child has a keloided scar that will forever be a reminder of the fall. The other has no visible proof that the fall ever took place. The moral of the story: Everyone heals differently. Just because you cannot see scarring doesn't mean they didn't fall.

LISA'S STORY

The effects of drug addiction flow from spouse to spouse just as they can be transferred from mother to child. Even though one partner may remain drug-free, the effects may surface through domestic violence and/or codependent behavior. Too many times the marriage ends with a tragic fatality.

After 15 years of marriage, Lisa was widowed with four children. Her husband died at age 40. She doesn't know exactly what he died from, but she is sure that his drug abuse contributed to his early demise. For the duration of their marriage Lisa's husband was addicted to alcohol and cocaine. The combination of drugs and marriage usually results in some form of abuse, and this marriage was no exception. Lisa gives the impression that she buried more than her husband when he died. The battered, mentally abused woman went with him at internment. She now describes herself as a "princess," a "king's kid." She says her faith gives her strength and her ongoing process of healing gives her a positive outlook on life. Her conversation reflects a healing with no visible signs of scars.

Lisa's life experiences allow her to do her job effectively. For the last year and 3 months she has been the parent/mentor coordinator and family specialist for a *SESS* center. She works directly with families. Sometimes her involvement causes heartache. She recently assisted an elderly woman with services for her 6-year-old grandson. The woman was diagnosed with breast cancer and the grandson has been



diagnosed with a learning disability. Lisa helped connect the woman with services that will assist her with her grandson while she undergoes chemotherapy.

Because she can relate to the needs of the family in crisis, Lisa is able to communicate effectively with them and for them. She has addressed government organizations on behalf of families at both the local and State level. She also is an advocate for African-American children who also are mental health consumers, addressing such issues as the maintenance of their skin and hair. She believes that a parent's voice should be heard, considered, and respected.

The horror stories of addiction are numerous. But in the midst of many of those nightmares are heroes. Sharon and Loretta are two of those heroes.

SHARON'S STORY

Sharon represents a *SESS* project in a major U.S. city. Sharon does not use drugs. However, she has chosen a career that puts her in direct contact with those who have suffered as a result of drug use. She is employed by a university medical center as the behavioral health specialist. Her position qualifies her for the role that she has had to play in the lives of her niece and nephew. She has epitomized what the *SESS* project stands for. She has removed her niece and nephew from a home where both parents were users and is raising them as her own in a secure environment.

In Sharon's family it is not uncommon to become a surrogate parent to those family members whose parents are unable to give adequate care. Sharon's mother opened her heart and her home to her nephew, because his mother was an alcoholic. He was raised with the rest of her children as a brother. Given the "sins of the father/mother" theory, it is sequential that this same nephew fathered two children that he could not care for because of drug addiction. Again, Sharon's mother opened her home to take care of a second generation of children. When it became more than her mother could bear, Sharon stepped in and became the primary caregiver. When confronted with the question, "what about the children," Sharon did not hesitate to come to the rescue of these children, despite having children of her own; not to mention the special care and attention needed by children who have had prenatal exposure to drugs.

The *SESS* project has been instrumental in securing counseling services necessary for Sharon's niece and nephew. They have suffered from separation anxiety, bitterness, and violent behavior.

Her mission as a family representative is to be able to better serve families by recognizing the strengths and weaknesses of individual

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programs and providing more family involvement. She would like to see more information and assistance for extended families that have custody but are not drug abusers. She sits on the *SESS* Advisory Council and is involved in decisionmaking and program development. Sharon's mission is to help the family play a more active role in constructing programs.

You can plan a pretty picnic but you can't predict the weather.

The trend today is to get in touch with yourself; rediscover who you are and give your life a makeover. Dig deep and discover your wants and desires, then "just do it." Feel good about you and your potential, then reach up and grab your potential, run with it, and achieve. The key to it all is having a clear vision of your dream. You must have a dream of your very own. After all, when was the last time you woke up in the middle of someone else's dream?

LORETTA'S STORY

Loretta woke up and found herself in the middle of her sister's nightmare. Loretta had been a very content, single, career woman. For 8½ years she had worked for the same company as a buyer. She was fairly established with a place of her own and money saved. Although she did not have children of her own she was quite content being an aunt to her sister's five children.

Loretta had followed through with the plans for her life. Drugs were not a part of that plan. Drugs were, however, through no fault of her own, a major component in the events that were about to change her life forever. Unbeknownst to Loretta, her sister was a drug addict. Since there was no previous drug abuse or use in her family, she was not familiar with the signs of addiction. Once Loretta found out that her sister was using, she exercised codependent behavior. In her efforts to help her sister she would give her money, but her sister would use the money to purchase more drugs.

Eventually Loretta realized that the true victims in this scenario were the five children. They were being neglected physically and emotionally. In fact, the two youngest children were visibly suffering from malnutrition, literally starving to death. She had to step in and help her sister's children.

Looking for services to assist her with parenting, Loretta turned to Head Start and signed up for their *SESS* Parenting Success classes. Then she was referred to another program, offered through *SESS*, that provided a special 10-week program that helped families work

Unbeknownst to Loretta, her sister was a drug addict. . . . Eventually Loretta realized that the true victims in this scenario were the five children. They were being neglected physically and emotionally. . . . She had to step in and help her sister's children.

together with the school program. Loretta was overwhelmed with the duties that a single mother has, coupled with the special needs of a child suffering from prenatal drug exposure. It was necessary to take a 6-month leave of absence from her job. Her days were filled with taking David to different doctors, counselors, or therapists. Because of her love for her nephew, Loretta found herself advocating for him, becoming the voice of this little boy who refused to talk.

After completing the 10-week program, Loretta signed up for an advanced phase of that training. At this time she became a parent liaison and has been on the fast track ever since. She has acted as a class and school monitor for Head Start. Since September 1999, she has been an assistant teacher. David's extensive schedule did not allow Loretta to return to her job. What she thought would be a temporary situation turned into a job in and of itself. Not only does she work for Head Start, she is also the parent liaison for the three training programs from which she has graduated. In June 2001, she traveled to Wisconsin to study to become a certified trainer.

Loretta is happy with the services she has obtained through *SESS*. David received one-on-one play therapy. Loretta also was taught the "special play" technique. David's progress has been excellent. His language skills have increased and improved. He is more cooperative and less aggressive in the classroom. His teachers say he listens very well, and he truly uses his words to express his feelings and needs. In fact David talks so much now, that Loretta says, "he needs a muzzle!"

Loretta knows that a voice can be heard from any family member. She would like to see more services that cater to non-drug-using family members who have custody of the children of drug abusers. To date, Loretta's sister is working in a fast food restaurant, but she is still using drugs. She has not been able to regain custody of any of her children. David is 4 years old and loves school. He has become a "poster child" of sorts at his school, capturing the hearts of the teachers and students alike because of his loving nature. The love of an aunt has been passed down to a nephew.





APPENDICES

APPENDIX A

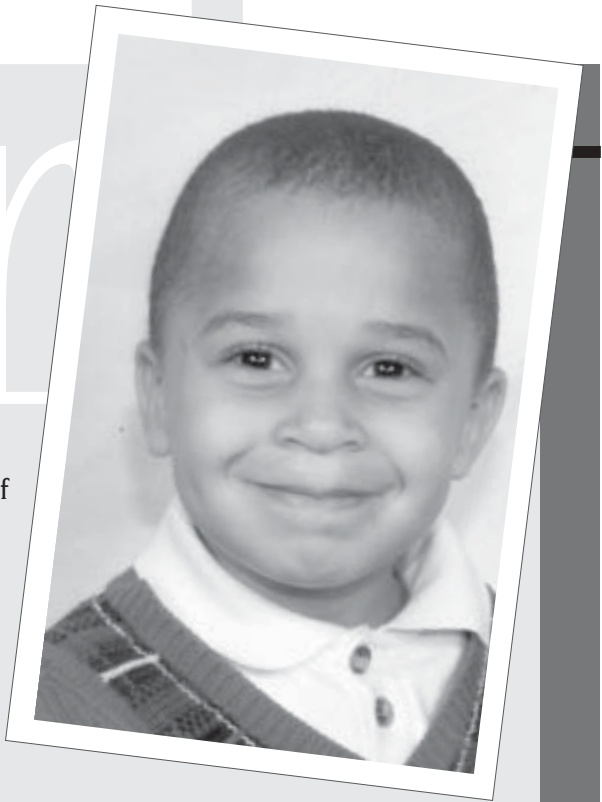
FAMILY MEMBER MENTORS AND FAMILY RESPONSE PANELISTS

ANGELICA ANDINO is the chairperson of the board of directors for Abriendo Puertas, a family organization in Miami, FL. Mother of three children, she is originally from Peru, but has lived in Miami for the last 25 years. She has been a part of Abriendo Puertas for 5 years and is driven by her desire to help others.

VALERIE BURRELL-MUHAMMAD, from Richmond, VA, is the family involvement consultant for the Federation of Families for Children's Mental Health. She is the mother of four children (two with mental health challenges). An advocate for her children since the early 1970s, she is committed to being a liaison between families and professionals. She longs for a system that values and recognizes everyone as part of the "human" family, regardless of race or class.

MANAJA HILL is a human being learning to respect himself and all that is around him. He is Hunkpapa Lakota, Mohawk, and Oneida, an enrolled member of the Standing Rock Nation. He is of the Loud Voice Thunder Tiospaye. The middle child of nine children, he was raised by his grandmother. He is a single parent raising three boys of his nine children. One of these boys has mental health challenges, which brings many lessons to the family. These lessons were the motivation for him to advocate for children with challenges and assist in the development of a Native American, parent-owned advocacy organization called Intertribal Voices of Children and Families.

D'ONICE RENCHIE-SYON, from Houston, TX, is one of the founding mothers of a family organization, Friends of the Family. This organization provides support to families facing various challenges, especially those regarding mental health. D'Onice is the mother of four children and grandmother of nine, two of whom live with her. She is a strong advocate for her grandson who has autism and excited about having the opportunity to participate in a forum that gives parents a voice in the children's mental health process.



APPENDIX B

SESS FAMILY ADVISORY COUNCIL MEMBERS AND FAMILY RESPONSE PANELISTS

LADONNA BONNER, representing *Starting Early Starting Smart*, Marin City, CA, is raising four children, three of whom have either learning or mental health disabilities. LaDonna has been an active parent representative for 3 years. She was originally a part of Family First and was recognized for her willingness to participate. In addition to being a full-time single parent, she is a junior, liberal arts major at Dominican University.

CHERIE CRAFT is the parent representative for the Boston Medical Centers RISE Program (Raising Infants in a Secure Environment). She is the mother of four children (two biological and a niece and nephew with behavioral and mental health challenges). Her mission is to better serve families by recognizing the strengths and weaknesses of individual programs and providing more family involvement.

LEANDRA GOUGH is the aunt/mother of a 3-year-old boy. She participates and works in the Head Start program at the *SESS* program housed at St. Bernadine's School in Baltimore, MD. A staunch advocate for all children, she is particularly interested in helping children whose lives have been impacted by drug abuse.

ROBERTA PAEZ is a 26-year-old mother of a 2-year-old daughter. She has been a parent participant of SELECTT (Starting Early to Link Enhanced Comprehensive Treatment Teams) for 1½ years in Albuquerque, NM. Roberta believes that through common hardships we can come together for early prevention.

KATRINA SHERMAN has been a parent representative of the Casey Family Programs, Spokane, WA, since March 2000. She is a 22-year-old mother of three children and is currently in the process of receiving her GED. Katrina credits the *SESS* program for helping her change her life.

LILLIAN WALKER is a single mother of five children. She works in the Las Vegas, NV, *SESS* program, New Wish, which is part of the Parent Training and Information Center. A former Head Start parent, she is a strong advocate for children and their families. She strives for the parent voice to be heard, understood, and respected.

EARTHA WEBSTER has been a committee member of the Healthy Start Coalition in Miami, FL, for 2 years. She is the mother of two children and is living her mission statement, "Each one teach one; Each one reach one."

APPENDIX C

ADDITIONAL FAMILY MEMBER PRESENTERS

JACKI MCKINNEY lives with eight grandchildren and one great-grandchild, many of whom have special needs. For 10 years she has been an activist for families and children. She has been involved in a number of research projects and is currently working on a SAMHSA-funded study on women with co-occurring disorders and violence, including issues around women with their children. In her life and her work she is committed to the intergenerational aspects of mental health issues.

SHANNON CROSSBEAR is a member citizen of Fort William First Nation of the Lake Superior Ojibwa, the mother of three and grandmother of two. Her previous work in evaluation has been done with the National Indian Child Welfare Association and the Research Center on Family-Based Services. Currently she is training Native families for the Individuals with Disabilities Education Act. Her life and work's purpose is to assist in creating balance.

GAIL DANIELS is the board president for the Federation of Families for Children's Mental Health. Gail is a single parent of three young adults, two of whom received mental health services for 12 years. She has collaborated with local and national organizations and agencies as a faculty advisor, advocate, and panelist.



APPENDIX D

SESS PROGRAM ACKNOWLEDGMENTS

The Families and Grantees of *Starting Early Starting Smart* (SESS) would like to acknowledge:

Nelba Chavez, Ph.D.
Administrator
Substance Abuse and Mental
Health Services Administration
Rockville, MD

and

Ruth Massinga, M.S.
President and CEO
Casey Family Programs
Seattle, WA

along with the Casey Board of Trustees and the three SAMHSA Centers—Center for Substance Abuse Prevention, Center for Substance Abuse Treatment, and Center for Mental Health Services—for their vision and commitment to reaching families with very young children who are affected by environments of substance abuse and mental disorders. Without their innovative public-private partnership and unprecedented support, this initiative would not have been possible.

We further acknowledge the early guidance and program development from Stephania O'Neill, M.S.W.; Rose Kittrell, M.S.W.; Hildy (Hjermstad) Ayers, M.S.W.; Karol Kumpfer, Ph.D.; Sue Martone, M.P.A.; and Jeanne DiLoreto, M.S. In addition, the advisement and investment of the U.S. Department of Education, and the Health Resources and Services Administration and the Administration for Children and Families of the U.S. Department of Health and Human Services were critical in this collaboration effort.

Many thanks to the SAMHSA-Casey Team for their tenacious efforts and unprecedented collaboration:

Joe Autry, M.D.
Acting Administrator
Substance Abuse and Mental
Health Services Administration

Jean McIntosh, M.S.W.
Executive Vice President
Casey Strategic Planning
and Development

Patricia Salomon, M.D.
Michele Basen, M.P.A.
Velve Taylor Spriggs, L.I.S.W.
Jocelyn Whitfield, M.A.

Barbara Kelley Duncan, M.Ed.
Peter Pecora, Ph.D.
Eileen O'Brien, Ph.D.

The Federation of Families wants to thank the SESS Family Advisory Council for its input and review of this document, as well as Monica Baker, primary writer. Special thanks also to Velve Spriggs and Eileen O'Brien for all of their support during this entire project.

APPENDIX E

STARTING EARLY STARTING SMART GRANT SITES

Study Site	Principal Investigator	Project Director	Local Researcher	Phone Number
Data Coordinating Center				
EMT Associates, Inc. Folsom, CA	Joel Phillips	J. Fred Springer, Ph.D.	J. Fred Springer, Ph.D.	(615) 595-7658
Primary Care Sites				
Boston Medical Center Boston, MA	Carolyn Seval, R.N., M.P.H., L.M.H.C.	Carolyn Seval, R.N., M.P.H., L.M.H.C.	Ruth Rose-Jacobs, Sc.D.	(617) 414-7433
The Casey Family Partners Spokane, WA	Christopher Blodgett, Ph.D.	Mary Ann Murphy, M.S.	Christopher Blodgett, Ph.D.	(509) 473-4810
University of Miami Miami, FL	Connie E. Morrow, Ph.D.	K. Lori Hanson, Ph.D.	Emmalee S. Bandstra, M.D. April L. Vogel, Ph.D.	(305) 243-2030
University of Missouri Columbia, MO	Carol J. Evans, Ph.D.	Robyn S. Boustead, M.P.A.	Carol J. Evans, Ph.D.	(573) 884-2029
University of New Mexico Albuquerque, NM	Andy Hsi, M.D., M.P.H.	Bebeann Bouchard, M.Ed.	Richard Boyle, Ph.D.	(505) 272-3469
Early Childhood Sites				
Asian American Recovery Services, Inc. San Francisco, CA	Davis Y. Ja, Ph.D.	Anne Morris, Ph.D.	Anne Morris, Ph.D.	(415) 541-9285 ext 227
Child Development, Inc. Russellville, AR	JoAnn Williams, M.Ed.	Carol Amundson Lee, M.A., L.P.C.	Mark C. Edwards, Ph.D.	(501) 968-6493
Children s National Medical Center Washington, DC	Jill G. Joseph, M.D., Ph.D.	Amy Lewin, Psy.D.	Michelle J.C. New, Ph.D.	(202) 884-3106
Johns Hopkins University Baltimore, MD	Philip J. Leaf, Ph.D.	Jocelyn Turner-Musa, Ph.D.	Philip J. Leaf, Ph.D.	(410) 955-3989
Division of Child and Family Services Las Vegas, NV	Christa R. Peterson, Ph.D.	Laurel L. Swetnam, M.A., M.S.	Margaret P. Freese, Ph.D., M.P.H.	(702) 486-6147
The Tulalip Tribes, Beda?chelh Marysville, WA	Linda L. Jones, B.A.	Linda L. Jones, B.A.	Claudia Long, Ph.D.	(360) 651-3282
The Women s Treatment Center Chicago, IL	Jewell Oates, Ph.D.	Dianne Stansberry, B.A., C.S.A.D.P.	Victor J. Bernstein, Ph.D.	(773) 373-8670 ext 3026

The *SESS* Sites

Miami's Families: *Starting Early Starting Smart*

Raising Infants in Secure Environments

Healthy Foundations for Families

Starting Early to Link Enhanced Comprehensive Treatment Teams

Casey Family Partners

National Association for Families and Addiction Research and Education

Child Development, Inc.

Asian American Recovery Services, Inc.

Locally Integrated Services in Head Start

Starting Early Starting Smart Head Start Collaboration Project

Baltimore BETTER Family and Community Partnership

New Wish

Beda?chelh Tulalip Tribes Early Intervention in Tribal and Mainstream Communities

Evaluation, Management and Training, Inc.

*One of the original *SESS* sites was unable to continue with the study, but it was an important contributor to the original design and implementation of this project. Our thanks to Dr. Linda Randolph and Dr. Ira Chasnoff.

**Data Coordinating Center

Florida

Massachusetts

Missouri

New Mexico

Washington

Illinois*

Arkansas

California

Washington, D.C.

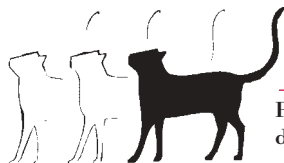
Illinois

Maryland

Nevada

Washington

California**



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Wide Web at
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CSAP Center for
Substance Abuse
Prevention
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Health Services Administration